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ABSTRACT

A social worker recounts the experiences of a long term support group of 12 (later 10) parents of children with neurological impairments. Originally begun as a time-limited parent group of children attending a therapeutic nursery program, the parent group has continued to meet into the children's adolescence. The group was initially led by two co-therapists but has continued with one leader. Although the parents have increasingly managed many aspects of the meetings, they continue to prefer an outside "expert" in the formal role of leader. Over the years, the focus of the group has changed from being completely about the children to covering the range of issues faced by the parents, including a marital breakup. This group's experience has led the agency involved to conclude that parent support groups may frequently be the treatment of choice for parents of special needs children. (DB)

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A LONG TERM SUPPORT GROUP FOR PARENTS OF NEUROLOGICALLY IMPAIRED CHILDREN

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1. Introduction

I am a social worker at the Child Development Center of the Jewish Board of Family and Children's Services in New York City. I have worked at the Agency for over 30 years. The most valuable professional contribution I have made has been my work with five couples, parents of neurologically impaired children. They have met as a group for more than ten years, starting when their youngsters were enrolled in our Therapeutic Nursery continuing to the present when the children are adolescents. I have been priveleged to be part of the development of this group and have learned from them of the tremendous impact an impaired child has on a family. The parents have gone through many stages and have stated repeatedly that much of the strength they have needed has been gained from the group experience. Over and over they have given testimony to the help they have offered each other and their sense that they were able to handle many dificult situations due to the support they received from each other. I want to share some of this extraordinary program and learning with you.

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2. Description of Setting and Rationale of Group

The Child Development Center runs a Therapeutic Nursery which serves 34 children, ages 2-1/2 through 5. About 12 years ago, the school's population shifted from children with mild to moderate emotional problems and a focus on early psychotherapeutic intervention and prevention to children with developmental, neurological and more severe emotional disturbances. Remaining cognizant of developmental and psychodynamic issues of each child and family, the professional staff struggled to develop a broader range of approaches and interventions to address the extremely complex range of problems facing these children and their parents. The CDC Nursery has

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always been part of a mental health agency and the parents have been involved in regular counseling sessions. Traditionally, they were seen once a week, individually or jointly.

In the Fall of 1983, six couples were invited to participate in a time-limited group which would meet on six consecutive Wednesday evenings and would supplement the sessions they had with clinical staff. We thought that contact with other parents facing similar problems would be helpful in a way that was not possible in individual meetings with educational and clinical staff. We believed that these group sessions would foster the sharing of feelings, parenting strategies, and information. Further, we anticipated that with the evening group, we would have greater success in involving fathers. And finally, expected that through this modality, we would learn more about how to meet the needs of this new group of Nursery parents. At the end of the six meetings, the group elected to continue meeting. In the following two years, the children aged out of the Nursery and moved on to other special education programs. Their parents asked to continue working as a group and to maintain their Agency connection. For the first two or three seasons, much of the May and June meetings were devoted to deciding whether to continue the Group for another season. After a while, it was taken for granted that the Group would remain together indefinitely. One family left when their child moved to a new school, but the other members have stayed together. One result of this group has been the current assumption at the Agency that parents of special needs children benefit from groups and they may frequently be the treatment of choice.

3. Choice and Characteristics of Group Members

In determining criteria for the group, it was decided to choose intact families and exclude people who seemed too emotionally fragile. Six couples were invited to join the group. They all had children who had been diagnosed as neurologically impaired. Five of the six families had a second healthy child. They were of a similar socio-cultural and intellectual level. They were well functioning people (many had previous personal therapy) who seemed ready to work on parenting issues. The group members were essentially healthy families who were dealing with disturbing events. Unlike most Agency clients who were concerned with inner psychopathology, these people were dealing with painful reality and legitimate worries.

All twelve group members were college educated, most with graduate degrees. Their professions included social work, music, law, medicine, higher education and business.

Mr. and Mrs. A. have a child who was diagnosed at six months with cerebral palsy. His parents were told he might be a retarded quadraplegic. He has had years of intensive therapy in several fields; speech therapy, physical therapy, psychotherapy. He left the Therapeutic Nursery as a child of better than average intelligence coping with learning disabilities, language problems, poor gross- and fine-motor control and emotional issues related to fear of failure and poor self-image. He has said "When the want is greater than the fear, I'll do it." His areas of strength are his ability to use his good intellectual endowment, his sense of humor, his insight regarding his own functioning. He remains cautious, is prone to regression, seems physically, emotionally and neurologically vulnerable and has not been able to develop age-appropriate social skills.

His lack of peer relations seems particularly poignant. His most satisfying social experiences are via a national computer program which allows him to communicate using technology which precludes face-to-face contact.

Mr. and Mrs. B.'s child has multiple difficulties in speech and articulation and overall motor control. These are secondary to a seizure disorder which began when the child was a year old and the side affects of the medication which controls the seizures. She has developed unevenly with great discrepancies among different areas of functioning. Seizure activity has continued, becoming more frequent since puberty. She is aware, self-conscious and angry about her seizures. She knows that she is different and worries about being embarrassed if she has a seizure away from home. She has said that when she grows up, she will wear big shiny earrings and not have seizures. Her social skills and capacity to become involved in good relationships with peers are a strength, but also an area of concern to her parents. She is beautiful and so eager to be liked that they fear she may be a vulnerable target. Continued seizures have caused brain damage which has resulted in severely compromised academic achievement. She was asked to leave the first school she attended after CDC because she was not learning and retaining, had "repeated" several grades and was physically too big for each new class. She is now at a school which accepts a broad range of functioning and is in a "Life Skills" class, learning practical strategies rather than academics.

Mr. and Mrs. C.'s child has one of the most severe communication problems we have seen at this nursery. Although his receptive language is good, his articulation is so poor that his expressive language is barely intelligible. In addition, his distractability and poor fine-motor control have seriously interfered with learning. His potentially good

learning capacity is compromised by his great difficulty in adhering to rules and school expectations. He challenges, pushes limits, and tests constantly. He has been suspended from school for explosive and aggressive behavior. He is unhappy about his inability to make friends, wants desperately to be a "regular kid and go to a real school." On occasions, he has been able to achieve beyond expectations. His Bar Mitzvah which will be described later in this paper.

Mr. and Mrs. D.'s child presents a complex set of problems. He had poor expressive and receptive language and delayed motor development. He is functionally retarded, yet has some areas of high capabilities, particularly in reading. His difficulties in relating or connecting with people interfere with most aspects of his functioning. He is seriously socially deviant. He has continued to develop as an unusual child, oddly related , in many ways idiosyncratic, yet able to handle himself surprisingly well in some situations. (i.e., was the first to go outside independently, ride his bike in the park, make "friends" among dog walkers, keep his sense of direction on a long bike ride in the country.) Despite some good academic achievements, he is in a "life skills" school program. At times, his extreme anxiety has made it near impossible for him to consider new experiences. He is a good candidate for medication, has taken Ritalin which has been helpul. At the beginning of puberty, he had several seizures.

Mr. and Mrs. E. have a child whose atypical seizure disorder started at the age of 16 months. He has seizures every night, and at times, during the day. His seizures are only partially and unpredictably controlled by medication. He has been hospitalized many times. The child is immature, functionally retarded and has poor articulation. He also has motor problems. This youngster's functioning has deteriorated more than any other

child of the group. The unrelenting and out-of-control seizure activity has seriously compromised his intellectual growth. Also, he has developed juvenile osteoporosis. Most of the time, he is a sweet natured child, but at times, he becomes oppositional (as a 2 year old) and can not respond to reason and verbal intervention. It is clear that he will never function independently, even with the help of a "life skills" program. His mother has said that his extremely low functioning can separate her from the other parents.

Mr. and Mrs. F. have fraternal twins. One developed a seizure disorder at the age of two, had limited language and a myriad of learning difficulties. When he aged out of the CDC program, his parents chose to leave the group.

4. The Leader's Role

When the group was started and for the first year and a half, I had a co-therapist. When he left the Agency, the group members decided it would be too difficult for a new person to "catch up" and I have worked alone ever since. Initially, there were many questions about what direction the group would take, especially since it was, in part, an attempt to learn better ways of serving these parents. We were not sure whether to emphasize parent guidance, self-help, a therapeutic focus, or a combination of these. Immediate reactions to the group provided no immediate clarity. There were moments when we felt as overwhelmed and inadequate as the parents seemed to feel. At other times, it was hard to determine whether the group needed leaders. It was enormously helpful to have another professional, particularly in the early sessions when there was so much powerful and poignant expressions of feelings. Handling the group alone

has resulted in many challenges. There have been many occasions when the support of another clinician would have been welcome.

Through the years, the members of the group have gradually taken more and more responsibility for the work of the sessions. They have become familiar with the many details of each other's current and past lives so that it is no longer necessary to identify relatives or explain past histories. They are sensitive and concerned for each other and inevitably, if one person seems to be challenged or pressured, another member asks if it is too much to tolerate. Frequently the question is asked just as I am getting ready to intervene. At most sessions, there is at least one occasion when I am unsure whether or not to interrupt the exchange of members, who, by now, talk to each other, rather than directing their remarks to me. I have generally handled this quandry by noting the issue and including it in my summary at the end of our meeting. I do claim the perogative of the leader when I think a member has not had suficient opportunity to resolve a problem or when a person has wanted to say something but was unable to get the group's attention. I usually reflect themes, connect them with past events, and encourage the group to look at the content, the affect, and to examine what it evokes in others. Twice, the group met without me. Although they reported that the sessions had been helpful, they did not want to consider the possibility of continuing as a leaderless self-help group. They have verbalized their need for structure, protection, and "an expert."

The primary task has been to set a tone ensuring that the group sessions offered a safe place for the expression of all emotions. Secondary to this has been the work of handling resistance to sharing uncomfortable material and helping the group define limits on the expression of inappropriate material (although as the years have passed, it has seemed that

nothing is inappropriate). It has been my job to modify distortions, such as their feelings of extreme helplessness or overwhelming guilt for sins of omission. Also, it has been important to make sure that the work of the group was done in the formal session and socializing saved for the time after I left. Despite moments of angst, reactive to the pain of the group members, I have generally felt great satisfaction after each session when I have reflected on my role in enabling the group members to talk together, share and help each other.

5. Group History and Themes

When I decided to write this paper, I reviewed years of notes to highlight the process and progress of the group members, their interactions, evolution of ideas and themes, the changes of attitudes, hopes and fears. I was constantly impressed by the power and poetry of the parent's statements and felt they describe their emotions far better than I could paraphrase. Therefore, much of the remainder of this paper is devoted to direct quotes.

At the first session, each couple told their story of coming to the CDC Therapeutic Nursery. They described their despair at the paucity of resources and frustration at the impossibility of locating appropriate facilities. They were angry at professionals who did not help them, or as one woman said, "A lot of the rage I felt toward the doctor was that I had expected him to make it all better." All expressed their great relief at finally finding CDC. They remembered with pleasure having met each other at previous experiences. (This was one of the first indications of their strong need for a support group.) They described their fury at relatives and friends who offered false reassurance and could not hear their pain.

They talked of their own sense of isolation and difference, compared to other parents and families. "It is not just our child who is different, we as a family are different." As each person spoke, the others nodded in agreement. Over and over, they evoked themes of sorrow, guilt, anger, and isolation. At the first session, the feeling of elation at having found each other and having shared important personal material with other couples who truly understood, made it difficult for the group members to leave each other. Long after the end of the session, they stood talking on the sidewalk in front of the building. This set a pattern for the group which had a formal therapeutic session with a professional leader, followed by an informal social period.

The value of the group was apparent and by the fourth session, the parents decided to extend the original six session contract. (Several years later, the schedule was changed to alternate weeks and later, to every three weeks.) At the end of the second year, when the children were ready to leave the Nursery, the parents elected to remain at the Agency. The focus of the group has changed many times. Initially, the parents talked about their children, sharing information (and anxiety) about finding schools, negotiating bureaucracies, locating resources and professionals they could trust. A few years into the group, a mother who teaches special education teachers said "I've learned more from this group about handicapped kids than through all my years of studying and teaching." Gradually, they discussed their own pain, their guilt, their anger, and their isolation. They were able to examine their strong feelings toward their children and the myriad of emotions created by being the parents of a special needs child. A father said,"Other parents of disabled children have instant credibility. I need to be with people who faces similar issues. I get nourishment from being in this group." There were also times when ambivalence and resistance were expressed. "I'm sick of it.

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The last thing I want to do is talk about my child." "The amount of time we all spend taking care of our kids is disproportionate to everything else." "Half my waking hours; my calendar overflows with appointments for him."

For the first three or four years, sessions during May and June were devoted to whether or not the group would continue the following year. Members weighed the pull of other demands on their time (increasing need to be with their children at homework time, the need for some respite and time off. "Maybe a movie would be more renewing.") against the value of remaining together, an on-going source of support. Each year, the decision was to continue, all members acknowledged the strength of the group relationships, the thought that the group "will be there" and the feeling that they could never duplicate such a reliable, predictable group to face on-going problems with them. It caused them to decide to "want to go through all current and future difficulties with each other." They recognized the variety of feelings and experiences that bind them together. "What unites us is the hopelessness." "Exhaustion is the major issue."

As the years continued, they lived through many individual crises and family events together. They developed into an unusual and atypical group. Unlike traditional therapy groups, they saw each other socially outside the sessions. They have become extended families for each other.

Group members used the sessions as a safe place to ventilate, explore and share a wide range of feelings, including those which at times were too painful, too unacceptable, too uncontrollable to acknowledge elsewhere. Frequently, one person's initial statement is picked up and enlarged by other members. One father has frequently expressed all the negative, rageful emotions that people seek to repress. When he described a

horrendous argument with his son which culminated with the father threatening to take back the child's bed and then tearing off the bed clothes, dumping the mattress on the floor and trying to pull the bedframe apart, a mother said "I laughed my head off because I was so scared." Later, the incident became a symbol for the uncontrolled, irrational, angry response that a parent might have to a relatively trivial event. Parents frequently spoke of the comfort they felt when another member verbalized something they were thinking. "Someone says something you are feeling inside and it breaks the isolation."

Group members grew to depend on each other. A mother was upset and close to tears following a bus ride when her son had raced up and down the aisle, shouting and people on the bus admonished her for not being able to control him. When she got off the bus, she telephoned her husband immediately. She could not reach him, so called a group member, knowing she could expect empathy and comfort. When one of the children had his first seizure, his mother diagnosed it because she had heard other parents talk about seizures. She called another mother for advice and a half-hour later the latter's husband came to the home to help. The second year, one of the families had a gathering for all the others, including the children and siblings. A father said "It was as if we had known each other all our lives. It was better than family; no criticism, no apologies, no competition, no bullshit."

When children entered adolescence, their handicaps were still present. They were no longer cute, appealing little kids. Families became aware of the lasting, probably life-long nature of the disabilities. One mother said "I have no fantasies left." Another parent: "I'm finally getting it. The bubble is bursting. I've realized that he may not go to college. I've given up my assumption that everything would turn out all right" and "I

feel I have a needle chipping at an iceberg. Each chip is a gem, but it's so hard and so long." With each other's support and understanding, members have forced themselves to move from seeing their youngsters as "late bloomers" with uneven development to accepting them as permanently handicapped young people who will be unable to make the hoped for leap into normality. "When I can accept him for what he is, it's fine, but I keep going back to wanting to make him into a normal kid." With this understanding, they have needed to face the overwhelming task of trying to plan for their children's future beyond the parent's life expectancy. The topic was raised when one couple was re-writing their will. Their initial concern was the financial planning. How would they provide for their healthy, high-functioning child and their disabled child? They knew they had to safeguard the future entitlements of their special needs child, yet protect him from total dependence on government care. Their financial advisor helped them plan appropriate trusts, but when they asked the mother's sister and brother-in-law to continue being guardians as had been planned years ago when they drew up reciprocal wills, the response was unexpectedly, "We're sorry, we can't." The parents came to the group describing the devastating experience. Before asking another sister, the mother wanted to know if the group would be available to help if it was necessary. "Will you help her find the right school, the best doctor, the emotional support? If you need it, I will do it for you." she pleaded. At this moment, the members became each other's extended family, promising to take an active role in the care of each other's children. Following this session, each couple had to face the same problem of trying to insure their child's future care. One mother felt she needed to save at least a hundred thousand dollars before she could ask somebody to take such a responsibility. Another wondered, "Who could I ask? Who would do it? Who has a good bond with my child? Who would really care, would not sleep at night if he isn't well? It's hard for me. What would it be like for

somebody who is not his parent." A different family: "We're so vulnerable; we don't have any extended family to take on guardianship. It's so overwhelming; we just keep putting it off." (This parent is a lawyer). And "I focus on our other child. What will it mean to her? I worry that she will have the responsibility.....and will take it, or won't. Either choice is dreadful for her." One family reported that their "healthy" child had assured them that they did not have to worry. He promised that he would always take care of his brother after the parents died. "It's unfair that he should even need to think about this." Another parent: "We've thought about having a third child to help our daughter, to share the burden of caring for our son." A father summed up by saying, "We have been forced to confront the future."

During the early years of the group, stress on the marital relationship was a topic frequently approached, sometimes examined, and at times, avoided. Members wondered if it was appropriate for a parents group to deal with couple issues. Once again, the topic was precipitated by events in the families' lives. A husband and wife who had been having great difficulty tolerating each other's reactions to their handicapped child decided that they could not continue living together and separated. The mother had been unremittingly depressed and the father needed to deny the lasting seriousness of the child's difficulties. For the group, this was the realization of many unspoken fears. They were in a position parallel to the child. How could they maintain a good relationship with each parent without feeling disloyal to the other? When the couple told the group what was happening, one of the members turned to me saying, "Do something. You must do something!" I shared the dismay and helplessness and needed to remind the group that lack of control is always painful. Initially, both parents continued to attend group sessions, but gradually the father dropped out, first because he had a conflicting meeting the night of the

group sessions and later, it was too hard to return. During this period, the group consisted of four couples and a single mother. All admitted that their children caused tension, and could challenge the marital relationships in many ways. They saw that the children were channels for their disagreements. One father reflected, "Children grow up and leave. We need to protect our feelings for each other." With time, couples began to share more intimate details regarding their interaction, what happened when they differed, felt unsupported, blamed each other for their child's problems. One mother recognized "When we're stressed, we become the targets of each other's upset." A couple used part of a session to confront each other, the wife stated that she always felt that she had primary responsibility for decision-making, that she was the one to take the child on all appointments and that her husband too frequently was a "cop-out." As she expressed her resentment, other women in the group added their experiences and they began to wonder if it was a gender issue. Group members became even more sensitized to the isolation of the single mother.

Over a year later, when the separated parents and their child were involved in family therapy in the Agency's out-patient department, the group leader had occasion to speak with the father and felt that he was strongly involved in his parental role. After talking to the mother, the question was raised with the group. How did they feel about inviting him to return to the group? Responses were varied, ranging from "I've always thought of him as a relative that we haven't seen in a long time" to "My parents and my brother are divorced and it is just too hard for me to establish a totally new relationship." When the wife was asked, she said, "At one time it would have been too hard for me, now it's all right. He is so alone in his efforts to deal with our child. We've been through a rough year and he's alone. He could use the group. I think he misses it. I have such faith in the value of this experience. It will help the whole

family." Ultimately, the group's concern about the father being so isolated prevailed. When the man came back, he was greeted with hugs and exclamations by all the other members. Since that time, he has not missed a session.

About four years into the group's history, they were asked to participate in an Agency cable television program. It would involve two group members and the leader discussing the program with an Agency public relations "host." Initial responses were very enthusiastic. Members wanted to do "something good for the Agency." They felt the concept of the group should be publicized. They hoped that the program would reach isolated families and enable them to reach out for contact with others who have similar problems. The P.R. department suggested that a mother and father who were not related would be the ideal participants. As this choice was discussed, other issues surfaced. The most powerful was that of "going public." By this time, all members were relatively comfortable in identifying themselves as parents of special needs children, but appearing on television, with no control over who would watch the program, presented a different challenge. A physician from a teaching hospital and a university professor who teaches special education, immediately said they could not feel comfortable with such public identification. A few parents were afraid they would not be articulate or might become too upset to cope with an interview on such a loaded topic. Finally, two fathers volunteered. One needed to take an active role which helped counter the many feelings of helplessness he frequently experienced. The second felt it was extremely important that their story be told and the program be made. After the video was completed and shown, the group talked of their reactions. A mother said she had not anticipated her strong emotions. As her husband stated the names of her two children, she had clutched herself and cried. One family was uneasy about their child seeing the video and

hid the copy they made, treating it as something forbidden and secret. Other members interpreted this as reflecting their complex ambivalent feelings regarding showing their children to the world. One of the fathers who had participated in making the video said that making it was no more exposing than going out of his home everyday. "Wherever we go with our child, we have gone public. He is a handicapped child and we are a handicapped family. It is obvious in a restaurant, a museum, on public transportation."

The social relationships formed outside the formal sessions of the group have been a great importance to the members. At several milestone events, all group members were invited to celebrations. At one mother's birthday, the group presented a joint gift, a day of relaxation and beauty at a spa, concretizing the frequent suggestion: "Do something for yourself." If a member's birthday fell on a session day, the spouse brought in something special to share. One meaningful event was the Bar Mitzvah of Mr. and Mrs. C.'s son. Everybody in the group followed the saga which started with the youngster saying: "I'm going to be 13 and I'm Jewish. Why can't I have a Bar Mitzvah?" moving to the parent's anxiety anticipating how difficult it would be for him to learn Hebrew (since he was still struggling with most of the articulation difficulties he had when he began to speak English), their concerns about his problems retaining information and most importantly, his unpredictable and at times, explosive behavior when he was frustrated. However, they agreed to his request and enrolled him in a Hebrew school for classes, supplemented by private tutoring. The entire group (including me) and all their children were invited to the Bar Mitzvah. Mr. and Mrs. C. had reported that at a rehearsal, the boy had bolted, locked himself in a bathroom and refused to participate. However, on Saturday morning, he was able to take his place next to the Rabbi and sing, chant, and speak all the parts he had prepared.

Although he had been reluctant to give a speech in English since he knew his articulation difficulties would be apparent ("everybody knows that you're not supposed to understand Hebrew,") he did talk about his Bar Mitzvah experience including having learned that "the most important thing is a person's mind and how good that person is, not if they are rich or poor, homeless, not the color of their skin, and not if they have other problems, like talking funny." He thanked all the appropriate people for "giving me the courage, helping me not to be too nervous, having confidence in me, helping me learn, even when I was stubborn." The Rabbi commented that no child had ever worked harder to prepare for Bar Mitzvah than this boy. Both parents, with much emotion, addressed him, acknowledging his learning disabilities and telling him how proud they were and how much they loved him. People attending the service spoke from their seats. His Little League coach, in a voice cracked with emotion, said that he felt such joy, even more than when the child finally got a hit that put him on base. A teacher talked of how much teachers learn from children. All tributes were moving and loving, with special appreciation of the child's courage and achievement. At a luncheon following the service, several group members talked of how wonderfully comfortable they felt about their children in this public place and attributed it to the open, accepting atmosphere created in the synagogue. It was a time when it was all right to have a child who might not behave according to expected norms. Echoing an earlier party, "no need to be embarrassed, no need to apologize."

During the years, the group has gone through many stages and has addressed many issues together. The changing focus has been in part responsive to the aging and development of the children. Parents have moved from their original hopeful question, "Will he be able to mainstream when he leaves the Therapeutic Nursery?" to accepting the possibility that their children may need life-long care. They have progressed from talking

about their children, to examining parenting, to sharing their feelings about themselves, to considering the impact of the disabled child on the family, the siblings, the marital relationships. They have been able to identify the constant presence of incipient feelings of rage and depression which can break through at any time. They have welcomed the group as "the only place where I can talk about my child and know that people will truly understand." The fathers particularly have depended on each other confirming that traditionally men have fewer confidants.

In their first year, the group developed the metaphor of a roller coaster to describe the ups and downs of their feelings and their lives; they have had to learn that this roller coaster does not stop, that they are on it forever. They cannot control its ups and downs, nor its speed. When their child takes a leap forward, they follow with joy and high spirits. But if their child regresses or when they face the inevitably painful situation of seeing their youngster with a mainstream child of the same age, they tumble. "You're in emotional free-fall, there's nothing to grab on to and get stability." As the years have gone on, there have been fewer highs, longer lows and a gradual acceptance. "I felt such relief when I realized I am not responsible for his bizarre behavior." Over and over, they have struggled with painful themes:

- They have needed to come to terms with their feelings of helplessness A father said, "We can only be resilient when we feel effective." When a mother was asked if she could try to stop being superwoman, she answered, "I'm trying. I used to think if I would try hard enough, pull an all nighter, I could do anything. But a long time ago, I had to give up the belief that I could accomplish anything I set my mind to." After seeing a woman in the street have a seizure, one mother said, "We try to protect our children, but I

can't control what happens. Her mother wasn't there to take care of her. I can't always be there." Yet another, "We're perfectionists. We've accepted less than the ideal and it doesn't feel good." The parent of a child with seizure disorder consulted somebody at N.I.H. "The smartest man I ever met. He couldn't help." They have all felt exhausted by inadequacy and helplessness. A father became teary as he recalled his child saying, "Make me better, Daddy."

- Rage and depression have become familiar emotions. Despite the best of intentions not to blame the children and their frequently stated intellectual understanding that it is not the child's fault, parents have been enraged at the youngsters for being something other than the fantasized baby, for all the emotional and financial burdens and for taking over the family. A father asked, "Why does it enrage me that I have a child who is so damaged?" Every parent has lost their temper, said things they wished they could forget, handled their children in ways that left lasting guilt. Another father reflected sorrowfully, "It's not only being embarrassed and angry, I don't like the kind of person he is becoming. There are times when I want to make him feel bad. When I use all the weapons in my arsenal to make him meet my expectations, I don't feel guilt. It's worse, I feel shame." "I felt like making him feel bad. It's a terrible feeling." When a mother talked of her sadness, she said, what happened to my child has become an emblem for all sorts of things. I used to think I could push through and spare myself and my child. Now, when I think of the future, I wonder if I can live with a child who will never..... I don't know if I will ever get over it. I don't want to be angry with him, but I get depressed when I think we'll be together forever. I'm burned out."

It has been increasingly difficult for group members to think about their children and themselves in the reality world with all its expectations and regulations. A mother reflected, "I've been living in a dream world, looking for his strengths and potential." When one mother expressed her distress about her child not yet reading, a father said, "If he never learns to read, isn't he still entitled to be loved by his parents? And aren't mothers and fathers entitled to feelings of disappointment?" A mother reflecting on the special education school her child attends said, "At school, they think the kids are so wonderful, but outside, in the real world, nobody will think they're so great." Parents repeatedly mourn their children's lack of achievement and minimal progress. "He goes through a lot of pain in the playground. He wants to be able to play with them. I'm not angry at him because he can't play ball. I'm in pain for his pain." Another parent: "He knows what he can't do and won't expose himself. He's getting bigger, but not developing. He's conscious of it and our reactions, that we're disappointed." Parents worry about how their children react to them. "A. is a happy kid. Why am I imposing my standards of what should make him happy? Last vacation, we were on a boat, seeing great things that he can never aspire to. Then I realized, it's my concern, not his. He's happy, has things that give him pleasure, he's satisfied. It's me." Another parent: "It's not only the deficits. She doesn't have friends. She's so lonely. She loves to hear about when I was a child. She wants friends, wants to grow up and go to parties and dances. I've seen how cruel the world can be to people who can't make it. That's my worst fear, that people may be mean to her." A mother reflected on her need to change her son. We seem to say to him, "We won't permit you to be so strange."

- Group members are concerned about the effect on healthy siblings, both because of the focus of the family on the impaired child and because of that child's behavior. Parents have come to feel that even their mainstream child is at risk. Their problems and daily functioning are overshadowed by the special child whose needs take precedence over all others. The siblings may be embarrassed and ashamed of their handicapped siblings and are then guilty about those feelings. They have noted role reversal when the younger child seems of take responsibility for an older handicapped sibling. A five year old answered an adult who asked if the older boy was retarded by saying, "No! He has trouble talking. It's hard for him to make some sounds." A parent described their daughter who strives for perfection, and said, "I don't know if she wants to make up for our disappointment or if she is afraid that his difficulties are contagious." Above all, the group members fear the complicated relationships that may occur when their children are grown and one may be called upon to take responsibility for the other.

6. Work of the Group

Initially, in the formal sessions, the parents used the time to share information and consider other issues related to care of their children. They have learned a great deal, accumulated a lot of information and can serve as a resource panel. But more than any other topic, this group has shown a profound need to share their special pain and to work through their strong feelings towards their impaired children. They have come to realize that their own negative reactions get in the way of their parenting and

place great stress on their relationships with other family members and with each other. "Through no fault of his, he has had a tremendous impact on our lives, and always will." They have come to feel that the entire family is at risk. After a holiday with extended family, a mother came to a group session and said she looked about her at all the relatives and realized, "we are a dysfunctional family, not just our child, all of us." Over the years, group members have poured out strong feelings of anguish, of rage and disappointment. The cohesiveness of the group has permitted expression of a full range of emotions with people agreeing, "This is a safe place. If we can't say it here, where could we?" Frequently the responses to one member's statement have been passionate. When a father described his cynicism and lack of hope for his child, a mother cried as she said, "What is so sad is that I don't think the world is going to make a place for our children." Each time a parent has grappled with the powerful feelings of anger toward their children or toward other people and institutions, the other parents have resonated to these emotions, nodding acceptance and adding experiences of their own. A father said, "Battles escalate. I feel beaten and abused. I'd like to abdicate, but can't live my life that way. Is the choice between battle and withdrawal?" The universality of their almost unacceptable emotions have made it possible for parents to acknowledge their feelings with less guilt and self-blame.

The members have discussed their feelings of burn out and their fear that there is little they as parents can do to determine the ultimate fate of their children. Much as they would like to control and impact upon their children's future, they have come to see that although they can handle many daily events, they do not have the power to control the many things that will influence the final outcome. A mother said, "I used to think that If I made sure he had enough sleep, ate well, had a good schedule, everything would be all right. Then I realized that whatever I

do, there's no control." One father asked, "How long do we still take responsibility for play dates? It was appropriate when they were 2 or 3, but at 15, at 25? When does it stop?"

Parents have found themselves caught between their sense that they have finally accepted their children's diagnosis and the implications and their need to keep hoping for a "magic bullet." They have generally been able to use the group as an understanding place to try to separate their wishes and their fantasies. As the children have grown older, parents have lesser aspirations and at times it has been the task of the group to urge a parent to hold on to hope and not give up. They all continue to want the child "to be all that he can be" and wonder "if he will ever be a well-adjusted handicapped child?" and "Acknowledging sadness doesn't help. Sadness begets more sadness."

The members' commitment to the group is strong, yet there have been times when they have needed to examine some specific problems. When one couple was repeatedly and regularly late, others took them to task and described their irritation, "I make it my business to get here on time, why don't you? Don't you value the group?" At times, the close relationships which have extended outside the group have interfered and members have felt hurt or have hesitated to say things which they felt might harm the friendship. At times, expectations of what group members could offer one another became unrealistically high, leading to occasional disappointments and resentments. There has been considerable effort my part to note these problems and verbalize them. Describing his feelings about the group, one father said, "There are two facets to the group, one is the meager help I can be to somebody else and the other what I get for myself. At times it is boring, but these are the dues I pay so that when I need the group, it is there."

Group members have said over and over that the strength of the group is in the cumulative experience. One member talks about a "forbidden" subject and that gives the others an opportunity to recognize it in themselves and permits them to think about something they had tried to suppress. They have tried to make a group pact to stop forcing their children to be something else and to let go of the anger at them for being what they are. A father said, "There's a long road ahead, yet I feel better with issues. It won't be pleasant, but we've learned to make decisions. Another parent, "I don't think time will heal. It may help last year's hurt, but there will be more." They have learned to be open with their children, acknowledging the youngster's limitations and letting them know that the parents understand it is not the children's fault. In a similar vein, they remind each other that it is not the parent's fault either.

6. Summary

In conclusion, many needs and problems have been successfully addressed by this group. Parents feel less isolated. They have a special community in which they can express concerns and feel understood. The group has been extremely cohesive. Frequently, members have made decisions based on the experiences of other members. Children have gone to the same schools and camps. At a group gathering, one couple was unable to attend due to illness, but their children went with another family. "We talk about you in a way that our kids think of you as close relatives." A major result of the work has been the parents awareness of how they relate to their children. Whether they are overly angry at the child, resentful toward demands, embarrassed about behaviors, disappointed by minimal progress, these parents have a fuller understanding of how their feelings affect

their children. A mother reflected, "It astounds me that we still get our ups and downs from him." They have been able to give each other permission for a vast array of difficult, uncomfortable feelings. When a parent said, "I feel as if my child is an intruder, pressing on my energy and time.", others knew exactly what was meant. Also, "It causes such angst to be on his case all the time." and "I've hit bottom, lost all my lightness, it's unbearable, nothing appeals to me." and "I can do things that give me a lift, but there is no spillover when I'm with my son. At times, I would wipe him out of my mind if I could." Members are totally accepting of each other's feelings and although they may try to help a person resolve or dilute a strong emotion, there is rarely a judgmental reaction or any other response that would make a group member feel that they need to censor their talk.

At this Agency, the group is unique. Indeed, in the professional community a group that remains together for over ten years is rare. All the members have had other treatment experiences, yet they repeatedly verbalize their conviction that the group has been the most helpful modality, combining the best aspects of psychotherapy and self-help groups. For the group leader, it has been the most exciting and rewarding endeavor of many years of professional experience.

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